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SCIENTIFIC CONTRIBUTION

Content of health status reports of people seeking assisted suicide: a qualitative analysis

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Abstract Two right-to-die organisations offer assisted suicide in Switzerland. The specific legal situation allows assistance to Swiss and foreign citizens. Both organisations require a report of the person's health status before considering assistance. This qualitative study explored these reports filed to legal authorities after the deaths of individuals in the area of Zurich. Health status reports in the legal medical dossiers of the deceased were analysed using content analysis and Grounded Theory. From 421 cases of assisted suicide (2001–2004), 350 reports on health status were filed. Many cases contained diagnosis lists only. Other reports had more elaborate reports revealing that some physicians were aware about the patient's death wish and the intention to solicit assisted suicide. Physicians' attitudes ranged from neutral to rather depreciative. Few physicians openly referred the patient to the organisations and supported the patient's request by highlighting a history of suffering as well as reporting understanding and agreement with the patient's wish to hasten death. In the health status reports five categories could be identified. Some files revealed that physicians were aware of the death wish. The knowledge and recognition of the patient's death wish varied from no apparent awareness to strongly supportive. This variety might be due to difficulties to discuss the death wish with patients, but might also reflect the challenge to avoid legal prosecution in the country of origin. To require comparable health status reports as requirements for the right-to-die organisations might be difficult to pursue.

Keywords Assisted suicide · End of life · Ethical decisions

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Introduction

Assisted suicide is legal in Switzerland and regulated by criminal law. Under Article 115 of the Swiss Penal Code, assisting in suicide with no self-interest is legal, provided that the person seeking assistance has decisional capacity (Bosshard et al. 2002). Committing suicide helped by another person is considered assisted suicide as long as the affected person self-administers the lethal drug.

Assisted suicides in Switzerland are facilitated mainly by four private right-to-die organizations: 'Exit Deutsche Schweiz', 'Exit ADMD' ('Association pour le droit de mourir dans la dignité"), 'Dignitas' and 'Exit International'. Unlike in the American state of Oregon, Swiss law does not restrict assisted suicide to cases of terminal illness and to physician assisted suicide (Ganzini et al. 2000). Nevertheless, the right-to-die organisations offer their services only after a stringent evaluation process. This process requires that the wish to die be deliberate and stable, the member suffering from a disease with a hopeless prognosis, combined with unbearable suffering or unreasonable disability. Therefore, the organisations usually want to have insight in medical records in order to objectify the patients situation. This occurs despite an on-going

debate whether disease respectively illness is rather a vague concept (Dekkers and Gordijn 2010). After agreeing to provide assistance, suicide is usually achieved with a lethal dose of sodium pentobarbital a prescription-only medication. It can be legally acquired only with a physician's approval.

The right-to-die organisations expect the person who wishes to hasten death to provide insights into his or her health status, as well as any relevant medical diagnoses and prognoses. Following the evaluation process the organisation refers the person to a prescribing physician, who assesses the situation anew via a personal encounter with the "solicitant," then decides whether to prescribe the lethal drug. A recent study revealed that of 421 cases, 25.9% involved prescriptions were written by the family physician, while 73.2% were written by the physician assigned by the right-to-die organisation. In only 2.7% of cases did the physician refuse to supply prescriptions at first and requested a second opinion (Fischer et al. 2008).

Having received the prescription, the solicitant schedules further attendance of a right-to-die organisation volunteer for providing help with the preparation of the suicidal act. After death has been confirmed, the volunteer must notify the police, who attend with a medical officer. All assisted suicides are treated as extraordinary deaths and are investigated by the authorities to determine whether the assistance violated Swiss law (Bosshard et al. 2002; Ganzini et al. 2000) The volunteer often also provides the medical officer with documentation, consisting of a physician's prescription and the medical records of the deceased (Bosshard et al. 2002; Bosshard et al. 2003a, b).

The present study is based on all 421 files of the Institute of Legal Medicine Zurich, the official body responsible for persons who committed assisted suicide facilitated by Exit Deutsche Schweiz (primarily assisting Swiss citizens) or Dignitas (an organisation that also provides assistance to non-Swiss) in the area of Zurich. Assisted suicide has been facilitated between January 2001 and December 2004, all of which were investigated by Zurich's Institute of Legal Medicine (ILMZ) (Exit, n = 147; Dignitas, n = 274).

Although the prudent decision making of the right-to-die organisation includes evaluating the solicitant's repeated death wish and unbearable suffering but has not to rely on the health status report by law, many files contained a health report. Since little was known regarding physicians' provision of medical records to confirm the patient's health status to right-to-die organisations, or their role in referring patients to right-to-die organisations, this qualitative study aimed to explore the medical records or letters of referral of patients who eventually committed suicide with the assistance of right-to-die organisations. Therefore, these documents (medical charts and referral letters of attending physicians) were examined on their content and possible statements of the physicians toward their patient's wish to hasten death. Since the report may contribute to the decision, we compared whether the content of the reports differed between fatal and non-fatal diseases, gender and origin of citizenship as Swiss and non-Swiss residents.

Methods

This study is one part of the qualitative component of a Swiss assisted suicide study. This study used qualitative content analysis on all files of health status report and a Grounded Theory approach on these files that contained statements to explore the reasons of physicians to support their patients' requests (Strauss and Corbin 1997, 1998; Glaser and Strauss 1967). The perspective and the rationales of the deceased addressed in their written accounts have been described elsewhere (Fischer et al. 2008, 2009).

Setting and data collection

From all 421 cases presented to the police as assisted suicides from January 2001 to December 2004 in the City of Zurich, 350 contained health status reports by a physician, which could be analysed starting in 2006. Dignitas files contained in 96.4% (n = 264) cases a health status report and the Exit files in 58.5% (n = 86) cases respectively and hence differed significantly in proportion between the two right-to-die organisations ($P < .000$). This is due to the fact that for Dignitas a medical report is a precondition that a solicitor of this organisation is given the "green light" to travel to Switzerland for a face-to-face medical examination carried out by a Swiss doctor whereas Exit that assisted primarily Swiss citizens which allows a face-to-face procedure only. The solicitants from whom the health reports could be analysed were Swiss citizens in 106 respectively Non-Swiss citizens in 244 cases.

Ethical consideration

The study was approved by the county ethics committee of Zurich in advance. In accordance with the approval requirements of the ethics committee, the files of all persons that had been assisted by one of the right-to-die organisation and were transferred to the Institute of Legal Medicine were transcribed by a collaborator from the Institute of Legal Medicine, who removed any identifying information. Only anonymized files could be analysed in the study.

Analysis

Descriptive analyses were performed regarding content of the physicians' documents pertaining to the health status of the patients (excluding the rationales of lethal drug prescription). All documents were categorized according to their subject matter, i.e., whether they contained only diagnosis lists, brief statements of prognosis or health status, extensive statements of prognosis or health status, or personal considerations of the physician regarding the patient's life situation (Mayring 2000). The documents that had extensive statements and physician's personal consideration were coded and analysed according to Grounded Theory methodology. For qualitative distinction of physicians' considerations and statements regarding their patients' life situations we used constant comparison methodology and coding strategies based on Grounded Theory (Strauss and Corbin 1990, 1997, 1998; Glaser and Strauss 1967). We organized the emerging categories via situational mapping (Charmaz 2006; Clarke 2005). Theoretical sampling was not possible since no new data could be obtained. Data analysis was performed using Atlas.ti software.

Eventually the categories of the health status reports were compared with their proportions among gender, fatal (cancer, cardiovascular/respiratory diseases, neurological diseases) and non-fatal disease (rheumatoid diseases, pain syndromes, mental disorders), as well as age of the people committing assisted suicide. Student's test and χ^2 were used to test for statistically significant differences.

Results

Of all 350 files, in 173 (49.2%) cases the report consisted of discharge information from a hospital, while 166 (47.3%) included the family physician's medical record. In 6 (1.7%) the physician of the right-to-die-organisation had made notes, and in 5 (1.4%) an attending physicians from an institution other than a hospital (nursing home, psychiatric clinic) had reported on the patient's health status.

Content of the reports

The content of the records were very diverse, ranging from diagnosis lists to extended personal statements by the physician, including referral to the right-to-die organisation.

The reports were eventually divided into five categories (see Table 1). (1) List of diagnoses (discharge information only), (2) discharge information with brief prognosis and reports of trajectory, (3) confirmation of the diagnosis written at the patients' demand and addressed "To Whom It May Concern", as well as (4) reports referring openly to the right-to-die organisation without personal supportive statements. The fifth category of reports was clearly written in support of the patients' wish to end life and for assisted suicide.

List of diagnoses

One hundred and sixty three (46.6%) medical record abstracts contained only diagnosis lists that contained no further information about symptom severity or information about suffering or patients' illness experiences. In cases of malignancies, the tumour stage was indicated.

Discharge information with brief prognosis and reports of trajectory

In addition to the list of diagnoses, the next 95 medical record abstracts (27.1%) contained statements about the progression of the disease.

A physician wrote, 112 days before death:

> Prognosis: Further deterioration, in the best case slow, has to be expected. In case of a surgical decompression a relevant improvement is not to be

Table 1 Content of the health status reports

	Total reports N = 350 (100%) n (%)	Exit n = 86 (24.6%) n (%)	Dignitas n = 264 (75.4%) n (%)	*P*-value
List of diagnoses (discharge information only)	163 (46.6)	29 (33.7)	134 (50.8)	$P < .000$
Discharge information with brief prognosis and reports of trajectory	95 (27.1)	22 (25.6)	73 (27.7)	NS
Reports confirming the diagnosis (written on demand to "whom it may concern")	39 (11.1)	4 (4.7)	35 (13.3)	$P < .000$
Reports referring openly to the right-to-die organisation without personal supportive statement	27 (7.7)	14 (16.3)	13 (4.9)	$P < .000$
Reports in support of the patient's wish to end life and for assisted suicide	26 (7.4)	17 (19.8)	9 (3.4)	$P < .000$

expected, but a stop of the progress could be achieved.

Prognoses were limited to descriptions of disease progression and were entirely independent of the patient's point of view.

Reports confirming the diagnosis to "whom it may concern"

In 39 (11.1%) cases, the report was written as a physician's confirmation of a diagnosis and was addressed "to whom it may concern." The lengths varied between brief reports of a few lines to more extended descriptions of the disease situations. Most files used medical terminology exclusively but symptoms were mentioned, merely confirming the seriousness of the diagnoses. There were little personal statements of the physician concerning the patient's point of view, but the description that further treatment had been suggested.

A neurologist wrote, 92 days before death:

> Certificate on demand To Whom It May Concern:
> The presented symptom constellation is in accordance with amyotrophic lateral sclerosis. The additional diagnostics with electrophysiology and liquor puncture showed no other reason for the progressive muscle atrophy. In addition to the current therapy I would suggest Vitamin C 1000 mg/day.

Few physicians stated (3) that their further treatment options had been rejected by the patient. In these cases the physicians appeared resigned to their patients' wishes but assessed themselves as unable to influence the outcome. These physicians indicated that mental health issues had been addressed with the patient.

Reports referring openly to the right-to-die organisation without personal statement

In 27 cases (7.7%) the reports were written as letters to the right to die organisation and addressed the patient's name. All names in the following quotes are changed.

In each of these cases the report indicated one of two approaches on the part of the physician. For the first of these, the physician reported on the patient's health status, which acknowledged the probability of increased deterioration, but avoided acknowledging the impact facing the patient in their near future. For the second, physicians described the increasing disabilities or suffering their patients had already experienced. Whenever the physicians reported in addition to reduced quality of life on increasing pain, this seriousness was stressed by the dependence on medication in order to bear these situations.

These statements both expressed the seriousness of the illness and highlighted the patient's suffering. Whereas most physicians revealed no personal position, making it impossible to glean whether they supported or rejected the patient's wish to die, some impartially acknowledged the patients wish to die.

Four months before death, a family physician wrote:

> Mrs Klein is a (x) year old lady who has been suffering for seven years from pain and progressive disability in her lower limbs related to degenerative lumbar spine stenosis. The symptoms gradually worsened and were accompanied by a weakness in the extensors of both feet as of two years ago. She cannot walk now without the help of two canes and has weakness and decreased sensitivity of both sphincteric regions.
> Medical management having failed to improve the situation, surgical procedure was decided upon 2 years ago, but refused by the patient on more than one occasion. In her current situation, surgery seems to be the only solution but is too risky now according to two eminent neurosurgeons consulted by Mrs Klein. She is severely handicapped with no hope of any improvement without surgery and she wishes not to have the operation because of the high probability of complications but end to her life.

Reports in support of the patient's wish to end life and for assisted suicide

In 26 (7.4%) medical records, the physicians supported their patients' requests openly, addressing the right-to-die organisation and explaining the seriousness of the illness and the constant wish to die. They emphasized the length and quality of their relationships with the affected persons and their families. These relationships were characterized as long-lasting, and involved careful consideration of all possibilities and open discussions of the issues surrounding death and dying.

These physicians presented comprehensive narratives of their patients' suffering. In each case, the disease was described and its progression highlighted, as was the patient's imminent loss of self-determination. The impact of the disease was viewed very broadly and could include the effect on the patient's family.

A family physician wrote, 30 days before death:

> Mrs Braun has been in my care for 13 years. She has been suffering from disseminated encephalitis with progressive trajectory for 27 years and a mainly hypokinetic-rigid Parkinsonism for 17 years. This is a non-curable chronic disease that leads to progressive

Table 2 Comparison between report categories and fatal/non-fatal illness, gender and origin of the diseased

	Total N = 350 (100%) n (%)	Fatal disease n = 245 (70.0%) n (%)	Non-fatal-disease n = 105 (30.0%) n (%)	Female n = 223 (63.7%) n (%)	Male n = 127 (36.3%) n (%)	Not-Swiss resident n = 244 (69.7%) n (%)	Swiss resident n = 106 (30.3%) n (%)
List of diagnoses (discharge information only)	163 (46.6.)	117 (47.8)	46 (43.8)	103 (46.2)	60 (47.2)	122 (50.0)	41 (38.7)
Discharge information with brief prognosis and reports of trajectory	95 (27.1)	74 (30.2)	21* (20.0)	60 (26.9)	35 (27.6)	72 (29.5)	23 (21.7)
Reports confirming the diagnosis (written on demand to "whom it may concern")	39 (11.1)	27 (11.0)	12 (11.4%)	27 (12.1)	12 (9.4)	32 (13.1)	7 (6.6)
Reports referring openly to the right-to-die organisation without personal supportive statement	27 (7.7)	17 (6.9)	10 (9.5%)	18 (8.1)	9 (7.1)	11 (4.5)	16** (15.1)
Reports in support of the patient's wish to end life and for assisted suicide	26 (7.4)	10 (4.1)	16*** (15.2)	15 (6.7)	11 (8.7)	7 (2.9)	19*** (17.9)

* $P < .05$; ** $P < .001$; *** $P < .000$

> deterioration of the bodily functions, especially mobility, despite extended medical and physical therapies and the use of many auxiliary measures. Meanwhile, Mrs. Braun is completely immobile. She can neither stay upright independently nor walk; she cannot eat by herself nor handle the electric wheelchair. There is a heavy Kyphoscoliosis of the spine with constant back and joint pain which is only bearable with constant use of pain killers and sleeping pills. As an after-effect, Mrs Braun suffers malfunction regarding micturition and bowel movement. The diseases have led to major nursing care necessity and increased psychological strain for the patient. I support her request for assisted suicide….

This group of physicians reported long relationships with their patients their families, assessed the appropriateness of the patients' requests and provided clear statements in support of the right to assisted suicide. In these cases, each statement was presented in full accordance with the patient, and highlighted the long history of the illness and the resulting deterioration. The patient's mental competence and capacity to be judicious were always emphasized.

In eight of the cases, the physicians had clearly signed lethal drug prescriptions and knowingly referred their patients to the right-to-die organisation for assistance.

Content of the health status reports compared with fatal or non-fatal diagnoses, gender and origin of residence

We analysed whether the content of the health care reports differed due to diagnoses, gender or origin of the diseased. From a total of 350 cases 245 (70%) were diagnosed with fatal diseases and 105 (30%) had a non-fatal disease. A total of 63.7% (n = 223) were female and 69.7% (n = 244) were non-Swiss residents (see Table 2).

In case of non-fatal disease more reports contained open support by the physician compared with those with fatal diseases ($P < .000$). Comparing of Swiss residents' with non-Swiss residents' cases, the proportion of reports with open support was statistically higher in the Swiss residents group ($P < .000$). Between women and men no differences in the content of the health reports were detected.

Discussion

This study is the first qualitative analysis of the health status reports in legal medical files pertaining to assisted suicide. The majority of the documents indicated a list of diagnoses with worst-case prognoses (malignancies) or contained at least a statement of unfavourable or even hopeless prognosis. Some reports were written on request of the person seeking assisted suicide and addressed "to whom it may concern". Few reports contained clear referral to the right-to-die organisations or open support and agreement with the patient's intention to seek assistance from Dignitas or Exit Deutsche Schweiz. Likewise, few included treatment recommendations that offered a hope of easing the burden of the illness.

The Swiss right-to-die organisations all require assessing the seriousness of each solicitant's medical condition; a physician's medical report was included in most files although it is not required by law. In principle, it is desirable that the appropriateness of the death request is discussed with the person and considerations of compliance with the principles of the organisation are undertaken

before medical files are requested, but health status reports might guarantee a rigorous examination of the patient's situation. However, the fact that health status reports may be considered necessary to be included in the files of persons seeking assistance does not imply that attending physicians outside the organisations have to agree with the person's request. The 2004 ethics guidelines of the Swiss Academy of Medical Sciences stipulate that, although Swiss law allows for assisted suicide, assisting suicide cannot be considered either a medical treatment or an obligation of a physician or other health care professional (Swiss Academy of Medical Sciences 2004). A UK survey revealed that only 2.6% of participating physicians thought that changing the law towards physician-assisted suicide would benefit affected patients (Seale 2006). A majority however voted against new regulation; the Assisted Dying for the Terminally Ill Bill (Finlay 2006).

Although we cannot accurately estimate the percentages, the available evidence suggests that, in many cases, the decision to seek assisted suicide remained undisclosed to the attending physicians. Legislation on assisted suicide in many European countries (Smith 2009; Trowell 2009; Bilsen et al. 2009) and regulations of the right-to-die organisations in Switzerland are discussed controversially (Ziegler 2009). It is possible that right- to-die organisations on this background explain that no need exists today to disclose the intentions of the help seeking persons to their physicians. In addition, since the right-to-die organisations suggest collecting all necessary information oneself, the person seeking assisted suicide might provide the available documents at hand without considering informing his or her physician. It is also possible that physicians of the 244 foreign patients knew about the patient's intention but were restricted in support their patient in order not to render themselves liable for prosecution.

Since a recent survey in Germany showed that approximately 40% of physicians could imagine themselves helping terminally ill patients to commit suicide, such as by providing drugs (Tuffs 2008), similar numbers might be assumed by the physicians who provided reports in this study. The percentage of physicians supporting their patients' requests might be even higher, although the numbers of agreement with the patients wish to hasten death has decreased over the last decades (Onwuteaka-Philipsen et al. 2003). Whereas in the 1990s, 64% of physicians agreed that people should have the right to decide about ending their own lives; in 2001 that number had fallen to 54%.

Surprisingly even when it could be assumed that the physicians would have known the purpose of the requested report (66 cases), the statements were written in a detached style, and only 21.6% of these files (13 cases) indicated a notion of the patient's death wish. In an US study 55% of the participating physicians reported that they would not include physician-assisted suicide in their practices even if it were legal (Hart et al. 2003). The detached style might indicate reluctance including such requests into physicians' practices. The reluctance might result also from misunderstandings between patients and health care professionals about the prognoses of the illness and the level of support patients expected accelerating death as it was described in the written accounts of the deceased (Mahrer-Imhof 2010). It needs further investigations to explore the correlation between physician's attitude, his or her communication skills and patients' revealing of death wishes. Physicians who clearly knew the intent of the documents, but did not indicate personal involvement, or even included depreciative comments at least reported on how the patients were affected by the illness. The prescribing physicians most often reported pain (55.8%), projected long-term care needs (37.0%), neurological symptoms (35.2%), and immobility (23.0%) (Fischer et al. 2009). Thus, the physicians report in this study emphasized similar symptoms.

The files presented to the legal authorities after assisted suicide contained open support for the person's request in 7.7% of the files. Compared with a recent survey among German physicians that showed only 3.3% to report having already supported a patient's wish to commit suicide, the percentage in this study was higher (Tuffs 2008). The supporting physicians described their support to be in accordance with the patients' wishes and rationales. Fischer et al. 2009 study however showed differences in the physicians' rationales and those of the deceased (Fischer et al. 2009). For example, the proportion on intention to control the circumstances of death differed widely between physicians and deceased; while 12.1% of the physicians pointed to this reason in 39.4% of all cases the deceased mentioned this as main reason. Since we only could analyse physicians' accounts, the agreement between physicians and person seeking assisted suicide were not known and only the physicians' perspectives could be emphasized.

The comparison between cases with fatal respectively non-fatal diseases showed that more supportive physicians' statements were written in case of non-fatal disease. Since the right-to-die organisations require that the member suffer from a disease with a hopeless prognosis, combined with unbearable suffering or unreasonable disability the process of evaluation might be even more stringent in case of non-fatal disease and therefore more elaborate reports were required in order to achieve assistance. Since unbearable suffering has been shown difficult to define, the physicians were prone to emphasize this in patient with non-fatal illness (Dees et al. 2010). Additionally, with a long history of suffering, patients might more openly discuss their wish to die with their attending physicians. It would be worthwhile to investigate whether open

discussions with physicians who do not pressure their patients either to agree to therapeutic measures or to seek assistance elsewhere might even result in fewer patients seeking assisted suicide. Avoiding "the either/or"—question, while considering all available means of alleviating the situation, would allow the patient to address thoughts about death openly and to reach a fully informed decision.

Limitation

A major limitation of the study was that we only had written accounts for analysis and had no further data source that could have provided insights in the communication process between patient and physician. We cannot assess whether or not physicians discussed the requests with the patients in person but did not reveal it in the report. Additionally physicians were unaware that their report would be analysed on its content and therefore a brief report might have considered being sufficient to support their patient's request by the right-to-die organisation.

Additionally, the sample may not be representative of all cases in Switzerland due to the fact that the data comprised all cases of Zurich. Whereas Dignitas main domicile was located in Zurich Exit had more sites to assist suicide throughout Switzerland from which the cases were not included in the study.

Conclusions

This study's results present a variety of health status reports included in the files of people that sought assisted suicide with two Swiss right-to-die organisations. Most of them were lists of diagnoses. In some cases, physicians' knowledge and recognition of their patients' intentions regarding assisted suicide was revealed. However, we assume that many physicians were unaware of their patients' intentions. This might be due to legal regulations in many countries that forbid support. Some physicians obviously have been confronted with the patients' death wishes and provided the health status report reluctantly or with no indication of their personal opinion. This group appeared to be involved but reserved, presenting their reports in a detached way. Finally, a small number of physicians were aware of their patients' wishes and openly supported them in their requests for assisted suicide. The latter indicate that end-of-life issues can be openly addressed between physicians and their patients. However, the detached or reluctant referral to the right-to die organisations by some physicians might be due to difficulties to discuss the death wish with patients, but also reflects the challenge to avoid legal prosecution in the country of origin. Comparable health status reports in every case as requirements for the right-to-die organisation might be therefore difficult to pursue.

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